BIRTH DEFECTS

CONDITION REPORTING

In Washington

The Washington State Birth Defects Surveillance System was an active surveillance system from 1986 through 1991. Since then, the system has been passive, relying on hospitals to report cases of children with birth defects. Currently, an enhancement project is in progress to develop a web based, electronic reporting system to reduce the reporting burden to hospitals. Washington State has around 80,000 live births every year with an estimated 2,400 to 3,200 children diagnosed with birth defects based on annual prevalence proportion of 2-4 per 100 live births per year. According to Washington State Vital Statistics 92 of 423 deaths to children under one year of age occurred among children with birth defects in 2000.

Purpose of reporting and surveillance

- Register the occurrence of selected birth defects throughout the state.
- Prepare summary statistics to indicate the magnitude and trends over time.
- Monitor emerging or unusually high occurrences of birth defects.
- Plan and implement preventive strategies to prevent selected birth defects such as, neural tube defects.
- Evaluate prevention strategies.
- Inform and educate the public, and make valid data available to policy makers.

Reporting requirements

In August 2000, the Washington State Board of Health approved a revised list of congenital abnormalities notifiable by law to public health authorities under Chapter 246-101 of the Washington Administrative Code. Among these were 9 birth defects and 3 developmental conditions.

Hospitals are required to report: anencephaly, spina bifida, cleft palate, cleft lip / palate, omphalocele, gastroschisis, limb reduction defects, hypospadias, and down syndrome, on a monthly basis to the Washington State Birth Defects Surveillance Program.

Autism, alcohol related birth defects, and cerebral palsy are also notifiable, but are on hold as they require different reporting procedures to be developed after the implementation of web based electronic reporting from hospitals has been completed.

Local Health Jurisdictions are asked to assist in educating health care providers regarding reporting requirement to the state.

CASE DEFINITION FOR SURVEILLANCE

Case definition

Case definition for Washington State Birth Defects Surveillance System is based on ICD-9-CM diagnostic and procedure codes as they appear in the hospital medical records. Any child up to age one year, diagnosed or treated, with a reportable birth defect that was a Washington State resident at the time of birth, or treated in a Washington facility is reportable. Information for all stillbirths over 20 weeks gestation diagnosed with a reportable birth defect should also be reported. Currently, we receive a completed hard copy form including the following data elements: Child's name, medical record number, date of birth, sex, admission date, zip code, discharge date, ICD-9-CM code for diagnosis, diagnosis, ICD code for procedure, and procedure.

Table. List of Currently Reportable Birth Defects and the Corresponding ICD-9-CM Codes

Disease Conditions	**ICD – 9-CM Codes**
Anencephaly	740.0 -740.2
Spina bifida	741.0 - 741.9
Cleft palate	749.00 - 749.04
Cleft lip	749.1 - 749.14
Cleft palate with cleft lip	749.2 - 749.24
Omphalocele	756.79
Gastroschisis	756.79
Limb reduction defects	755.20 - 755.4
Hypospadias	752.60 - 752.62
Down syndrome	758.0

A. Description

1. General

Birth defects are inborn syndromes, diseases, disorders and malformations that occur before birth. They can affect the organs, senses, limbs, physical and mental development. They also cause pregnancy loss through miscarriage and stillbirth. Some conditions are recognized at birth, others become apparent later in life. Birth defects are the leading cause of infant mortality in the United States, accounting for more than 20% of all infant deaths. Of about 120,000 U.S. babies born each year with a birth defect, 8,000 die during their first year of life. Birth defects are the 5th leading cause of years of potential life lost and contribute substantially to childhood morbidity and long-term disability. The health care cost associated with birth defects is also immense.

2. Cause(s)

The cause(s) of about 70% of all birth defects are unknown. Environmental pollutants may cause birth defects, developmental disabilities, or other adverse reproductive outcomes. Similarly, occupational hazards, dietary factors, medications, infections, and personal behaviors may cause or contribute to birth defects. The causes of birth defects may be a defect in any part of the genome, an interaction between genes or between genes and the environment.

3. World Wide Occurrence

Congenital abnormalities may occur any where in the world. It is possible to see random or systematic geographical variation in the occurrence of some forms of birth defects. This could be due to certain genetic factor(s) or due to a specific exposure.

4. High risk factors

Factors that can cause an adverse outcome of pregnancy exist in the environment, where some are known and most of them are not. In addition to what genetic factors may contribute, exposure before or during pregnancy to factors such as smoking, alcohol, medications, illicit drugs, or dietary factors may predispose a pregnant woman to have a child with one or more abnormalities.

B. Methods of Control

1. Prevention Activities

Education of health professionals and the public regarding factors that may be related to birth defects is crucial for prevention. The use of folic acid, a B-vitamin (B9) found in fortified foods and vitamin pills has been shown to be effective in reducing the incidence of neural tube defects. The U.S. Public health Service recommends that all women who could possibly become pregnant get 400 micrograms (or 0.4mg) of folic acid every day. This could prevent up to 70% of some types of serious birth defects. But to do this, women need folic acid before they get pregnant. Since over 50% of births in Washington are unintended, it is important to promote daily consumption of folic acid to all women of childbearing age. In addition, early identification of birth effects promotes care coordination and secondary prevention activities to improve the quality of life.

2. Occurrence of Clusters

The occurrence of a new or an already known congenital abnormality in a cluster is an indicator of exposure to a known or an unknown factor(s) or may be by chance. Suspected clusters (3 or more cases of the same or developmentally similar conditions) may be reported to Asnake Hailu, the Washington State Birth Defects Surveillance Coordinator at

(360) 236-3591 or to Juliet VanEenwyk, the state epidemiologist for non-communicable conditions at (360) 236-4250.

3. International Measures

Once a teratogen or a risk factor proves to be causal, that knowledge should be communicated internationally and appropriate measure should be taken to avoid exposures. Efforts to prevent exposures of pregnant women to Thalidomide, Aminopterin, Isotretinoin all over the world are examples of this kind of international effort.